The Hope And Unkept Promise Of Brain Cancer Clinical Trials

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By Sundas Hashmi

Roughly 12,000 people are diagnosed with glioblastoma (GBM), the most severe form of brain tumor, every year in a US population of 330 million people. That makes this cancer rare. It is also deadly: most GBM patients die within 12-16 months and only 5% survive for five years or longer.

Such stark statistics raise a glaring question: are we — in the richest country on Earth — doing enough to advance treatment for this terrible disease?

The answer is a resounding no. Not only are we far from finding a breakthrough that would turn GBM from terminal to treatable, but completed clinical trials for brain cancer are actually declining.



In a **new study**, scientists at the Carle Illinois College of Medicine, Dana Farber, and Stanford University found that over the past two decades:

- Federal funding for brain cancer clinical trials has decreased from 47% to 24%.
- A meager 50% of the US population affected by brain cancer diseases have limited access to clinical trials.

Perhaps the most shocking finding of all was that brain cancer clinical trial completion rates have significantly decreased — from 78% to 64%.

In short: we are going backwards.

So, what exactly are these clinical trials and why are they so important?

Clinical trials are research studies for new drug applications to the US Food and Drug Administration (FDA) and are urgently needed to advance treatments and cures. They are generally conducted over 4 phases: phase 1 to establish safety of the drug, phase 2 to judge its effectiveness, phase 3 to see if it's more efficacious than the treatment that most GBM patients receive, and finally stage 4 to seek approval and if successful, distribute it to the market.

Clinical trials stand out amidst the bleak landscape of GBM treatment, where patients typically receive surgery, followed by a toxic and ultimately ineffective regimen of chemotherapy drugs and radiotherapy (i.e. beams of intense energy to kill cancer cells). Clinical trials allow patients actively to take part in their own health care, give them a semblance of hope, help them gain early access to a promising drug before it goes through FDA approval, and let them do their part to advance science and help patients who come after them.

If clinical trials are so promising, why does it take so long to get their benefits to patients? Traditionally, the process of drug development and approval has taken anywhere from a whopping 7 to 15 years.

Hope lies in the FDA's accelerated approval strategy: authorizing drugs much faster for serious diseases with few existing treatment options. Glioblastoma would be a perfect candidate for such expedited treatment.

Additionally, the FDA's Orphan Drug Act offers incentives for rare disease treatment development, such as tax credits, fee waivers, and seven years of market exclusivity.

A couple of recent clinical trials have generated some interest. There are dendritic cell vaccines, such as DC Vax, that stimulate the immune system to attack cancer cells.

Then there are oral pills, like Vorasidenib, that target certain mutations found in brain tumors.

(More information on relevant clinical trials can be obtained via clinicaltrials.gov, through the healthcare team, and on non-profit websites such as braintumor.org and abta.org.)

So far, these new treatments often only extend survival by a few months and are far from the breakthrough that is so desperately needed.

That's one of the reasons OurBrainBank exists: We are a non-profit committed to raising awareness about this woefully underserved community of people devastated by GBM. Our mission is to support families and to demand more resources and action that will move the disease from terminal to treatable.

Join us today to make this possible.

Sundas Hashmi is a member of the US board of OurBrainBank, an international non-profit that is sounding the alarm on behalf of GBM patients and families in both the US and the UK. Please contact us at info@ourbrainbank.org if you would like to help, or visit our website www.ourbrainbank.org for information about this terrible disease and how to demand more resources for urgently-needed clinical trials.

To find out more about OurBrainBank, or to support OBB's work, visit its website. Follow OBB on Twitter or LinkedIn.



OurBrainBank

OurBrainBank is an innovative, patient-led movement designed to move glioblastoma from terminal to treatable, powered by patients. It's the first non-profit created by, with, and for people living with glioblastoma, an aggressive and rare brain cancer. Founder Jessica Morris (1963-2021) survived for five years after her diagnosis. The five-year survival rate is 5%. We believe in patient power and the importance of donating data to medical research. Patient-driven data is the new currency in medical research. OurBrainBank is a registered nonprofit 501(c)3 based in the US and registered charity in the UK.

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